



REVIEW AND COMMENTARY

The Right to Die in Chronic Disorders of Consciousness: Can We Avoid the Slippery Slope Argument?

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ABSTRACT

Managing individuals with chronic disorders of consciousness raises ethical questions about the appropriateness of maintaining life-sustaining treatments and end-of-life decisions for those who are unable to make decisions for themselves. For many years, the positions fostering the “sanctity” of human life (i.e., life is inviolable in any case) have led to maintaining life-sustaining treatments (including artificial nutrition and hydration) in patients with disorders of consciousness, allowing them to live for as long as possible. Seldom have positions that foster “dignity” of human life (i.e., everyone has the right to a worthy death) allowed for the interruption of life-sustaining treatments in some patients with disorders of consciousness. Indeed, most ethical analyses conclude that the decision to interrupt life-sustaining therapies, including artificial nutrition and hydration, should be guided by reliable information about how the patient wants or wanted to be treated and/or whether the patient wants or wanted to live in such a

condition. This would be in keeping with the principles of patient-centered medicine, and would conciliate the duty of respecting both the dignity and sanctity of life and the right to a worthy death. This “right to die” has been recognized in some countries, which have legalized euthanasia and/or physician-assisted suicide, but some groups fear that legalizing end-of-life decisions for some patients may result in the inappropriate use of euthanasia, both voluntary and nonvoluntary forms (slippery slope argument) in other patients.

This review describes the current opinions and ethical issues concerning end-of-life decisions in patients with disorders of consciousness, with a focus on the impact misdiagnoses of disorders of consciousness may have on end-of-life decisions, the concept of “dignity” and “sanctity” of human life in view of end-of-life decisions, and the risk of the slippery slope argument when dealing with euthanasia and end-of-life decisions. We argue that the patient’s diagnosis, prognosis, and wishes should be

central to determining the most appropriate therapeutic approach and end-of-life decisions for that individual. Each patient's diagnosis, prognosis, and wishes should also be central to legislation that guarantees the right to die and prevents the slippery slope argument through the establishment of evidence-based criteria and protocol for managing these patients with disorders of consciousness.

INTRODUCTION

Consciousness is the condition of normal wakefulness (opening and closing eyes, preserved sleep-wake cycle) and awareness (of the self and environment) in which an individual is fully responsive to thoughts and perceptions, as suggested by his or her behaviors and speech.^{1,2} A disorder of consciousness (DOC) results when awareness and/or wakefulness are compromised because of severe brain damage.³

In recent years, the advances in diagnostic procedures and intensive care have increased the number of patients who survive severe brain injury and enter a vegetative state (VS) (also recently named *unresponsive wakefulness syndrome*)^{4,5} or a minimally conscious state (MCS). These entities represent the two main forms of chronic DOCs.⁶⁻⁹ In particular, patients suffering from VS are unaware of the self and the environment and cannot show voluntary, purposeful behaviors because of severe cortico-thalamo-cortical connectivity breakdown^{10,11} that globally impairs sensory-motor processing and cognition. On the other hand, patients with MCS show fluctuant but reproducible signs of awareness and have a limited repertoire of purposeful behaviors.

The best management of patients in VS and MCS requires a correct diagnosis, an evidence-based prognosis, and the full consideration of the medical, ethical, and legal elements concerning DOC.¹² In particular, patients with DOC need artificial nutrition and hydration

(ANH) and, often, intensive treatments. These issues evoke a thorny ethical problem concerning the therapeutic decision-making of such patients (including the continuation of life-sustaining therapies) in view of the uncertainties about their state of consciousness, prognosis, and personal wishes, with particular regard to the end-of-life decisions (ELD).¹³ In fact, it is worth remembering that the implementation of any life-sustaining treatment, including ANH, should not be automatic when considering that every individual should make his or her own decisions regarding any kind of therapy, according to the ethical principles of autonomy and the right of self-determination and freedom. If an individual is unable to make a decision, as in the case of patients with DOC, a surrogate should be empowered to ensure the patient's best interest and personal wishes concerning ELDs. Therefore, the right to lose health, become ill, refuse treatment, live the end of life according to one's personal view of life, and die should be guaranteed, which is in keeping with human dignity and the duty to protect physical and mental health.¹⁴

The right to die is further supported by the following arguments.¹⁴⁻¹⁹

1. The right to (a worthy) life implies the right to (a worthy) death.
2. There is no reason to have a "dedicated" right to die, given that dying is a very natural phenomenon, as is life.
3. Death is a private matter, and other people have no right to interfere if there is no harm to others or the community (a libertarian argument).
4. It is possible to regulate euthanasia by proper laws, and thus avoid the slippery slope argument (SSA).
3. Euthanasia may avoid illegal acts, given that euthanasia may happen anyway (a utilitarian or consequentialist argument) and

save the extreme despair of suicide or homicide.

6. Death is not necessarily a bad thing, owing to the naturalness of the phenomenon, regardless of whether it is induced.
7. Euthanasia may satisfy the criterion that moral rules must be universalizable, but universalizability is a necessary but not a sufficient condition for a rule to be morally good.
8. Medical resources can be better managed, and though this is not a primary reason for the right to die, it is a useful consequence.

On the other hand, an opposite view states that life is a unique and incorruptible gift that, in keeping with the concept of the sanctity of human life, must always be preserved. Hence, each individual has the moral duty to attend to all the treatment necessary to preserve life, with the exception of those burdensome and/or disproportionate to the hoped for or expected result (i.e., life preservation), and to avoid behaviors that can deliberately hasten or cause death.^{13,19-24}

A possible middle ground is represented by the concept that the sanctity and the dignity of life are somehow coincident; consequently, there is no reason why accepting euthanasia makes some individuals worth less than others. Since it is possible to regulate euthanasia by proper laws, there is no risk of the following.^{13,19-24}

1. Starting an SSA that leads to involuntary euthanasia, thus killing people who are thought undesirable
2. Less than optimal care for terminally ill patients (for economic reasons)
3. Giving too much power to medical staff in limiting the access to palliative and optimal care for the dying, pain relief, saving lives, using euthanasia as a cost-effective way to treat the terminally ill, and limiting the research for new cures and treatments for the terminally ill

3. Exposing vulnerable people to pressure to end their lives (duty to die) by selfish families or by medical staff to free up medical resources or when patients are abandoned by their families.

At first glance, the problem of ELDs in patients with DOC may seem easy to solve. The supporters of the dignity of human life claim that since patients with DOC are unconscious and therefore cannot fully benefit from their rights, ELDs should be assumed by a third party (e.g., those with whom the patient is familiar, medical staff, ethics committees, or courts).²⁵ These parties would make the ELDs, taking into account the best interests of the patient, his or her wishes, the right to freedom, and the respect of human dignity. On the contrary, those who advocate the sanctity of life deny any possibility to hasten (by interrupting life-sustaining treatments) or cause death (by using euthanasia and physician-assisted suicide) (PAS), because they believe that life preservation is a social and ethical duty. Moreover, patients with DOC are in a very frail and vulnerable condition in which they cannot express their thoughts on these issues.^{13,19–24}

Judgements in the Schiavo and Englaro cases highlight this controversy. In the Schiavo case,²⁶ the argument was over whether Terri Schiavo was in a persistent VS, which had already lasted 15 years. It began with her collapse in 1990, due to cardiac arrest, and then her husband's initial court attempt to have her feeding tubes removed in 1998. That was followed by court battles between the husband and Schiavo's parents, who opposed the removal of the feeding tube. Her feeding tube was removed several times and then reinserted after more court orders. It was removed for the last time in March 2005 after the last successful court petition by the husband. Schiavo died 13 days later.

Likewise, Eluana Englaro²⁷ entered a persistent VS in 1992

following a car accident, and subsequently became the focus of a court battle between supporters and opponents of euthanasia. Shortly after her accident, medical staff began feeding Englaro with a feeding tube, but her father "fought to have her feeding tube removed, saying it would be a dignified end to his daughter's life." According to reports, Englaro's father said that before the car accident, his daughter visited a friend who was in a coma and afterward told him, "If something like that ever happened to me, you have to do something. If I can't be what I am now, I'd prefer to be left to die. I don't want to be resuscitated and left in a condition like that." The authorities refused father's request, but the decision was finally reversed in 2009, after she had spent 17 years in a persistent VS.

Of note, the United States Supreme Court has stated that the irreversibility of a DOC condition and the clearly defined patient's wish to not live under such conditions should both be clearly demonstrated in order to withdraw the sustaining therapies, including ANH.^{28,29} These decisions are fully in keeping with the right of freedom and self-determination and with the supporters of the right to life. However, these are fiercely criticized and hindered by the sanctity of life supporters.^{13,19–24}

Therefore, we consider whether it is more ethical to respect human dignity than to protect the sanctity of human life at all costs. A correct approach to this thorny ethical dilemma requires taking into account that there is a tangible uncertainty of DOC diagnosis and prognosis, consequently making it more difficult to respect a patient's rights properly when making ELDs. Moreover, it is still debated whether ANH should be considered a fundamental (i.e., always due) or an aggressive therapy (i.e., useless and bearer of further suffering).^{22,24,30–34} Finally, the motivation sustaining the right to live with dignity and in respect of human life sanctity must be analyzed

carefully, given that the access to the right to die is a SSA. In fact, both the withdrawal and the maintenance of ANH may lead to a chain of related events that may culminate in some significant and potentially negative effects on patients with DOC (e.g., death or unnecessary and prolonged suffering). Liberalizing euthanasia may lead to unnecessary application in some cases. The strength of each argument in favor or against ELDs depends on whether one can demonstrate a process that leads to a significant effect. SSAs can be used as a form of fear mongering in an attempt to scare the audience, thus ignoring the possibility of a middle ground between the dignity and the sanctity of human life. In this article, we will review the key concepts of the positions supporting the dignity and the sanctity of human life in an attempt to find a conciliating view to solve the SSA.

DOC DIAGNOSES AND PROGNOSIS

When family members are faced with an irreversible and hopeless case of unconsciousness, leaving their loved one in such a condition may be unbearable for both the patient and his or her family members. The relatives of patients with DOC live a paradoxical reality. In fact, they live with a family member who is both present (inasmuch as he or she is awake) and absent (unaware) and alive (inasmuch as he can open and close his or her eyes, breathe independently, and make some movements) and dead (given that he or she cannot interact with the family members or the environment).^{35–37} These issues can foster denial or misunderstanding in the family members of their current situation. For example, they may deny that their loved one is in a VS because they interpret spastic or reflexive movements as signs of improvement,⁶ thus imagining chances of recovery that are not supported by evidence-based medicine. Given that the family

members may witness important responses by the patient that have not been observed by the clinicians, the medical staff should attempt to observe the patient with the family members and involve them in the patient evaluation. Assisting family members in better understanding the patient's behaviors and level of awareness is important and may strengthen the family members' relationship with the medical staff.³⁸

Hence, the correct communication of a proper diagnosis and a reliable prognosis is essential for the best management of a patient with DOC. In fact, inaccurate diagnoses and prognoses and disclosure of false diagnostic information to families may have serious ethical, medical, and legal consequences regarding the medical management of the patient, the well-being of patient's family members, and ELDs.^{39,40} In fact, an incorrect diagnosis and prognosis may result in a false expectancy for recovery by the family members, the unnecessary and potentially harmful life-support prolongation of the patient, financial and emotional resources being withheld or withdrawn, resource misuse and misallocation, and an inappropriate rehabilitation or long-term care facility enrollment.¹³ Nonetheless, identifying residual awareness in unconscious patients (thus differentiating VS from MCS) and establishing a correct prognosis are extremely challenging, owing to the inadequate sensitivity of the clinical and paraclinical approaches currently available for DOC diagnosis and prognosis.^{41–47} Even though the rate of consciousness recovery varies from eight percent to 72 percent (but decreases to 20–30% in patients persisting in comas longer than 24 hours),⁴⁷ a severe brain injury may result persistent unconsciousness for many years. There have been cases of emergence from DOC, even after many years.⁴⁸ Generally, recovery from a metabolic or toxic coma is far more likely than from an anoxic one where the traumatic brain injury (TBI) occupies an intermediate

prognostic position. A post-anoxic coma is a state of unconsciousness caused by global anoxia of the brain, most commonly due to cardiac arrest. The outcome after a post-anoxic coma lasting more than several hours is generally, but not invariably, poor.⁴⁷

About 40 percent of patients with VS may be clinically misdiagnosed in that they may be conscious but are unable to manifest any signs of consciousness.^{49–51} Such a condition has been recently labeled *functional locked-in syndrome* (FLIS), whereby, using neurophysiological and functional neuroimaging approaches, clinicians are able to record residual brain network connectivity that is sustaining a covert awareness.⁵² A patient with FLIS is clinically similar to one with VS, with the exception that the former is aware of the self and the environment but is unable to demonstrate awareness or communicate.^{6–9} This may due to the deterioration of sensory-motor processes, which support motor function, rather than the breakdown of cerebral connectivity.^{6–12,53,60}

The low rate of correct diagnoses and prognoses may depend on the variations in scale application, awareness fluctuation, and subjective interpretation of clinical findings. The use of paraclinical tests to detect residual and covert signs of awareness may help in better managing patients with DOC and consequently supporting their right to ELDs. Nevertheless, different paraclinical tests would be necessary to confirm awareness since single tests may suffer from the same methodological bias that clinical approaches do.^{39,40,54}

ELDs AND THE DIGNITY OF HUMAN LIFE

The thought of interrupting life-sustaining treatments, including ANH, may arise in family members and caregivers when their loved one suffers from a long-lasting and potentially irreversible DOC condition.³⁴ The idea of hastening

one's own death may occur when one's quality of life is poor or unbearable (e.g., in the case of physical pain and/or mental anguish) and life is considered without dignity (e.g., feeling there is no chance of recovery, finding nothing that makes life worth living, and perceiving life as a burden to others).^{55–58} One might consider that respecting the dignity of life means respecting the dignity of death and thus avoiding unbearable and/or unnecessary suffering or living in what one might considered a handicapped and hopeless condition. As stated by Marc Augé,⁵⁹ "To die without dignity is to die alone, abandoned, in an inhospitable and anonymous place, in a non-place. To die without dignity means to die, suffering needlessly or to die tied up to a technical gadget that becomes the sovereign of my last days. To die without dignity also means to die in isolation, surrounded by insensitive people, soulless specialists, and bureaucrats who carry out their professional tasks mechanically."

Many authors^{22,24,30–34,60–62} criticize using the interruption of ANH as a way to hasten death because ANH suspension inevitably leads to a lengthy death with the potential for suffering, and suffering would be considered an unworthy way to die. This reasoning suggests that ANH should be continued in order to avoid suffering by the patient, even when that patient is unconscious.^{61,62}

Others argue that ANH is a standard part of treatment for patients with DOC, and suggest that the discontinuation of ANH along with any other standard treatment should be permitted when explicitly requested and that this is in keeping with the principles of beneficence and non-maleficence and the "patient's best interests" rationale.^{63–65}

However, the rights to freely live (with obvious due respect for others) and to make any decision concerning one's own personal health are well established as respecting the principles of free will and the personal understanding of the quality

of life and human dignity.⁶⁶ This suggests that a human being has an innate right to be valued and respected and to receive ethical treatment. In 1964, the *Declaration of Helsinki*⁶⁶ stated, "It is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects." Such issue was further corroborated by the Council of Europe in 1997 in the *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*⁶⁷ and by the United Nations Educational, Scientific, and Cultural Organization's *Declaration on the Human Genome and Human Rights*⁶⁸ in 1998. Both of these councils stated that there is an absolute need for respecting the human being both as an individual and as a member of the human species, for recognizing the importance of ensuring the dignity of the human being, and for safeguarding human dignity and the fundamental rights and freedoms of the individual with regard to the application of biology and medicine.

In keeping with the duties and rights set forth in the aforementioned declarations, a competent individual or an individual's surrogate should be free to make ELDs. We might consider that ANH contributes to the physical well-being of the patient and permits a continuation of life and, possibly, improvement in the quality of life. And in cases of long-lasting VS where the chances of recovery are slim at best, we might consider that withholding ANH might cause physical and/or emotional pain. One might also consider, however, that when the burden of life on the patient outweighs the benefits (e.g., in the case of a patient with DOC who has no chance of amelioration), the administration of ANH might be futile treatment. Even the most conservative positions on life

maintenance, e.g., the Catholic church, admit that treatments are not obligatory when considered harmful.⁶⁷ Hence, a form of passive euthanasia might be acceptable when 1) aggressive or unnecessary therapies in cases of terminal or hopeless illness only prolong a painful and suffering life, 2) an informed request is made by a sentient patient or, conscientiously, by that patient's surrogate(s); and 3) death is an unintended, although foreseeable, consequence of therapy interruption. In this regard, the unique scope of therapy interruption must be to avoid the suffering of the patient and not to provide or hasten death. Thus, the most conservative positions will deny any form of euthanasia but will provide palliative care, even if this shortens the patient's life, thus producing the unwanted and undesired side effect of death (passive euthanasia).

ELDs IN VIEW OF THE SANCTITY OF HUMAN LIFE

The right to die is strongly criticized by those who claim the sanctity of human life and argue that the willingness to die should be considered unacceptable for moral, religious, logical, and philosophical reasons.^{13,20-24} In fact, it might be argued that euthanasia and PAS can be similarly compared to suicide and homicide, respectively, even when performed at the explicit request of the patient or surrogate, given that they cause death with established methods and times. As argued by the most conservatory positions (including the Catholic Church),^{13,20-24} this issue is considered by some as unacceptable because life is an inviolable gift (by God or nature) that cannot be removed by self or by others. The expression *sanctity of life* refers to the idea that human life is sacred and holy, given that A) all human beings are to be valued, irrespective of age, sex, race, religion, social status, or their potential for achievement; B) human life is a basic good as opposed to an instrumental good—a good in itself

rather than a means to an end; and C) human life is sacred because it is a gift from God. Therefore, the deliberate taking of human life should be prohibited except in self-defense or the legitimate defense of others.

In religion and ethics, the inviolability or sanctity of life is a principle of implied protection regarding the aspects of sentient life, which are said to be holy, sacred, or otherwise of such a value that they are not to be violated.^{13,20-24} Hence, by merely existing, every human being lives his or her own life with dignity, which includes living correctly, according to moral and ethical principles. This suggests that one must die in a natural way, given that death is a natural phenomenon. Death might be considered the 'last page' of life, and life must be experienced with dignity. One's death has been decided by the superior Being, and thus one should adopt options of preservation, including the administration of analgesics and the provision of adequate human, psychological, and spiritual support, which may relieve the sense of solitude and allow relatives to grieve and be given the opportunity to humanize death. On the other hand, the voluntary refusal of treatment may lengthen the patient's period of suffering but will still result in death as a result of the disease itself, not by any action or omission of life-sustaining therapy. In such cases, death would be natural and expected.

Some secular positions criticize the right to euthanasia and PAS from a logical point of view.^{28,29} They claim that it is unreasonable for one person to determine the death of another person as there could be a reasonable chance of healing, survival, or alternative care. In addition, they argue that such a determination should not be made due to the inherent uncertainty of the chances for recovery and real level of awareness in patients with DOC (e.g., a patient may be in a state of FLIS, thus unable to

communicate with those around him or her but is still aware). Hence, using this line of thinking, we might conclude that patients with DOC should always have the right to live and to die peacefully and naturally later rather than have their lives prematurely ended by removing a feeding tube, which would lead to forced starvation.

MAKING CHOICES

We might consider in what way the worthiness of life is defined, since “worthy” is the pivotal element of the right to death argument. An important component of ELDs is each individual’s perception of what makes life important, worthy, and valuable. For example, one individual might perceive that living with a disability makes his or her life unworthy, whereas another individual with the same disability may consider his or her life important and worth living. Therefore, one might argue that the dignity of one’s life has to be determined by oneself, as long as such determination does not harm others, including family members. From this point of view, dignity and sanctity of life are not conflicting, and ELDs for patients with DOC could be based on sufficient evidence that their condition is irreversible and hopeless and any ELDs are in keeping with their wishes. It could be argued that putting an end to unnecessary suffering is not an affront to but rather a strengthening of the sanctity and dignity of life, provided this end is freely and consciously wanted by the either the patient or his or her surrogate on behalf of the patient.

A clear and conscious decision to request the discontinuation of one’s own life-sustaining therapy, including ANH, may serve as sufficient legal justification for such a decision in most United States courts as long as the patient is an adult who is capable of making decisions. But what about in cases of DOC, in which the patients lack the capacity to make decisions, and thus the burden of

decision falls on the patient’s surrogate or guardian? In the United States, the *Quinlan* and *Cruzan* cases highlight two important considerations regarding the ethical admissibility of ELDs made by a patient’s guardian or surrogate when the irreversibility of unconsciousness has been established: 1) making a presumptive decision for the patient in the absence of a living will and 2) making a decision for the patient with a living will.^{68–70} Based on the principle of substituted judgment, in some states in the United States, a surrogate is allowed to refuse life-sustaining treatment on behalf of the patient, with or without a living will, if the patient lacks the capacity to decide for him- or herself and the treatment is considered burdensome and/or unnecessary (i.e., the patient will never recover, even with treatment). In these cases, withholding or interrupting life-sustaining therapy would be considered to be in the best interest of the patient. In other states, however, a surrogate must provide evidence of a living will that satisfactorily communicates the patient’s desire to have life support discontinued in the event of irreversible DOC—before the surrogate can make such a request.^{68–70}

The ethical admissibility of ELDs made by a patient’s guardian or surrogate becomes thornier when dealing with cases of MCS, because these patients may have residual decision-making capacity and cognitive ability. There are several cases in the United States where ANH was withheld in patients with MCS (e.g., *Conroy*, *Edna*, *Martin*, and *Wendland* cases).^{71–73} Because MCS individuals are partially conscious and are not typically terminally ill, their legal status is complex. While consciousness itself might be a good reason to continue life-sustaining aids, it may not always be in the patient’s best interest to continue living a severely handicapped life.^{74,75} Determining when existence is no longer

subjectively valuable for an individual with a severely limited capacity to communicate is a vexing situation. Assuming that all persons have the same right to die, MCS surrogates should remain empowered to act on behalf of these vulnerable individuals,⁷⁶ but also should take into account the potential that their loved one with MCS might still have some cognitive ability.

Altogether, the ethical issues surrounding ELDs made by someone other than the patient highlight the importance of establishing living wills, which are written, legal instructions regarding a patient’s preferences for medical care (doctors and caregivers) if he or she is unable to make decisions for him- or herself because of a terminal illness, severe brain injury, coma, the late stages of dementia, or the near-end of life. By careful planning, unnecessary suffering of the patient and burdening the caregiver with difficult ELDs might be avoided during times of crisis or grief. Through the power of attorney, a person (healthcare agent, proxy, surrogate, representative, attorney-in-fact, or patient advocate) is empowered to make decisions for the individual who is unable to do so. Living wills are allowed or legalized in the United States (e.g., California Natural Death Act⁷⁷ and United States Patient Self Determination Act⁷⁸), Germany, France, Canada, Australia, Denmark, and England, whereas they are still debated in Italy.^{79–81} However, a living will may present some critical problems. For example, a patient’s wishes may not be respected due to the lack of clear legislation concerning the warranty of the patient’s right to die. The medical staff’s rights and duties also may not be clearly defined, causing further push back on respecting an individual’s living wills by raising the concern about potential criminal consequences of an omission or fulfillment of patient’s will.⁸² Furthermore, the disproportionality of therapies has not been clearly defined.⁸³ Some may argue that a

dying patient has the right to refuse burdensome medical treatments that A) have no chance of curing or improving the patient's medical condition(s) and/or B) are disproportionately painful, intrusive, risky, or costly when compared to the expected therapeutic outcome. It can be argued that every individual should be free to decide whether to live in such a condition. But regarding the living wills of patients with DOC, it is important to consider not the value of the life of the person but rather the value of the treatment to that person.

To avoid potential problems regarding the authenticity of living wills, they should be officially certified by means of a notary or an audio-video testimony overseen by a lawyer or a solicitor. Moreover, a living will should be checked and updated continuously to confirm the desires of its author in terms of ELDs in general and ELDs specific to DOC, should this occur. And finally, the possibility of revising the will of an incapacitated patient regarding withdrawal of ANH and other life-supporting care may need to be considered, with the help of family members and friends. Living wills prepared in such a way will reduce the chances of misinterpretation of the document by judges, ethics committees, and public health committees.

THE SLIPPERY SLOPE ARGUMENT (SSA) OF THE "RIGHT TO DIE"

After considering the ethical dilemma of maintaining a patient's dignity while respecting his or her sanctity of life, the issue of how to regulate the right to a worthy death remains. In fact, the lack of a clear position by those governments that have not established ad hoc laws on ELDs has led to the growth of the phenomenon of indirect euthanasia, in which pain medication is administered to the patient to reduce pain, with the side effect of quickening the dying process.⁸⁴ One might consider that the primary intention of such treatment is not to

kill the patient but to make the patient more comfortable, which might be viewed as morally acceptable. This type of indirect euthanasia might be justified using the "Doctrine of Double Effect," which states that if doing something morally good has a morally bad side effect, it is ethically correct only when the bad side effect is not intended, even if the bad effect was foreseeable.⁸⁵ That is to say the good result must be achieved independently of the bad one, the action must be proportional to the cause, and the patient must be in a terminal condition.

Without clear euthanasia legislation, arbitrary nonvoluntary and even involuntary euthanasia could potentially occur.⁸⁵ Euthanasia must be voluntary to be ethical, but it is nonvoluntary when it is used in unconscious individuals or in persons who are unable to make a meaningful choice between living and dying and an appropriate person (a surrogate or a legal guardian) makes the decision on their behalf. On the other hand, nonvoluntary euthanasia can also be when the person who dies had chosen life but instead underwent euthanasia at the request of someone else (i.e., murder). A conservative view is that this SSA could lead to an out of control acceptance of euthanasia or PAS, even if it is deemed unacceptable.^{13,20-24} From a logical point of view, if the acceptance of an initial act logically entails the acceptance of another (but undesirable) act, it might be argued that there is no relevant conceptual difference between the two acts. And on the other hand, if the acceptance of an initial act will lead to a series of similar acts that are all acceptable, the eventual last (and unacceptable) event is not relevant. From an empirical or psychological point of view, one could argue that there is instead no need for a logical connection between two events; the acceptance of an event will, in time and through a process of moral change, lead to the acceptance of another one.

To avoid an out of control application of ELD, and to both grant and regulate the right to die, governments in the United Kingdom, Canada, and some states in the United States have outlined different protocols for ELDs and euthanasia. A clear law that limits ambiguity regarding the representation of patients with DOCs is still missing in many countries, including Italy. The media has brought attention to some cases that have forced the courts to decide whether to suspend ANH, but no clear, consistent legislation with documented protocol has been established when considering euthanasia for patients with DOC.^{27,69,86-91}

Active euthanasia, in which a person (physician or not) directly and deliberately causes the patient's death following that patient's explicit request (or that of the patient's surrogate) through the use of drugs is legal in a few countries. As of June 2016, euthanasia of this nature is legal in the Netherlands, Belgium, Colombia, and Luxembourg.⁹² PAS (which refers to cases wherein the person, who is terminally ill, needs and asks for the help of medical professionals in ending his or her life) is legal in Switzerland, Germany, Japan, and Canada; it is also legal in the states of Washington, Oregon, Vermont, Montana, New Mexico, and California in the United States.⁹²

The Netherlands has legalized both euthanasia and PAS but only after the patient had received every available type of palliative care. In 2004, the Groningen Protocol⁹³ was developed establishing the required criteria each case must meet before legal child euthanasia may be carried out, which protects the liability of the physician. It is worthy to note that Belgium also allows child euthanasia when the young patient is conscious of his or her decision, understands the meaning of euthanasia, and suffers from a terminal illness that causes an intractable and unbearable pain; the child's parents and the medical team must approve the request.⁹⁴

Luxembourg and Uruguay legalized euthanasia for terminally ill patients, who have received the approval of two doctors and a panel of experts.^{94,95}

Switzerland allows PAS for both adult citizens and foreigners, whereas PAS is legal in Canada only for all adult Canadian citizens with a terminal illness that has progressed to the point where natural death is “reasonably foreseeable” (the Assisted Dying for the Terminally Ill Bill).^{96–100} Likewise, Colombia approved euthanasia for terminally ill patients with cancer, acquired immunodeficiency syndrome (AIDS), kidney or liver failure, and degenerative diseases (including Alzheimer’s, Parkinson’s, and amyotrophic lateral sclerosis) that cause extreme suffering.¹⁰¹ In Germany, PAS is legal as long as the lethal drug is taken without any help, meaning there is no one guiding or supporting the patient’s hand.¹⁰²

Active euthanasia is illegal throughout most of the United States, whereas the passive form (i.e., refusing medical treatment even if this choice may hasten death) is legal, with PAS being legal in five states (Oregon, Washington, Vermont, California, Montana, and one county in New Mexico). The legislation passed in Oregon, Washington, and California was based on Oregon’s “Death with Dignity” Act,^{103–107} which states that a “competent adult resident who has been diagnosed by a physician with a terminal illness, which will kill the patient within six months, may request in writing, from his or her physician, a prescription for a lethal dose of medication for the purpose of ending the patient’s life. The exercise of the option, under this law, is voluntary, and the patient must initiate the request. Any physician, pharmacist, or healthcare provider who has moral objections may refuse to participate.” Two witnesses, one of whom is not related to the patient in any way, must confirm the request. After the request is made, another physician

must examine the patient’s medical records and confirm the diagnosis. The patient must be determined to be free of a mental condition that impairs his or her judgment. If the request is authorized, the patient must wait at least 15 days and make a second oral request before the prescription may be written. The patient has a right to rescind the request at any time. The patient must be referred for a psychological evaluation if the physician has concerns about the patient’s ability to make an informed decision or if he or she suspects the patient’s request may be motivated by depression or coercion.^{103–107}

Oregon’s Death with Dignity Act protects doctors from liability provided the adult patient is competent and is in compliance with the statute’s restrictions; at the same time, this Act also guarantees and regulates the access to the right to die. Participation by physicians, pharmacists, and healthcare providers is voluntary. The law also specifies that a patient’s decision to end his or her life shall not “have an effect upon a life, health, or accident insurance or annuity policy.” According to the *Oregon Death with Dignity Act: Data Summary 2015 Report*,¹⁰⁶ about 64 percent of the people in Oregon who filled prescriptions for lethal medications died. There were no significant differences concerning age, gender, or levels of instruction. The primary end of life concerns were the loss of autonomy, the inability to make life enjoyable, and loss of dignity. Notably, there was no evidence of heightened risk for euthanasia in the elderly, women, the uninsured, people with low educational status, the poor, the physically and mentally disabled, the chronically ill or unconscious, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities compared with background populations.¹⁰⁸

In Oregon, futile or disproportionately burdensome treatments, including ANH, may be

withheld or interrupted under specified circumstances and only with the informed consent of the patient or, as in the case of VS, with the informed consent of the legal surrogate. The United States Patient Self Determination Act does not address quality of life issues and does not make a clear distinction between active and passive euthanasia when there is clear and convincing evidence that the informed consent to euthanasia, passive or active, has been obtained from a competent patient or the legal surrogate of an incompetent patient.

Active euthanasia is explicitly illegal in Australia, Austria, China, Denmark, Finland, France, Ireland, Italy, Latvia, Lithuania, New Zealand, Norway, the Philippines, Russia, Spain, Turkey, and the United Kingdom, though some will allow access to advanced care directive options and offer reduced penalties for those who assist patients in dying. In Denmark and France, a sort of “Right to Die with Dignity” act is under debate.⁹²

Passive euthanasia, as described earlier, is legal in India, Sweden, and Ireland. Moreover, passive euthanasia is tolerated in the United States, Mexico, Canada, Israel, Argentina, Hungary, Finland, Thailand (even for foreign individuals), Portugal (with the exception of ANH interruption, which is not allowed), and Germany. In Japan, there is a law plan for active euthanasia and PAS. The plan includes clauses related to an unbearable and untreatable suffering (for which the physician must have ineffectively exhausted all other measures of pain relief), inevitable and approaching death, and a written consent (living wills and family consent will not suffice). Interestingly, Japan’s government instituted “bioethics SWAT teams,” which are made available to the families of terminally ill patients in order to help them, along with the doctors, come to an informed decision based on the personal facts of the case. In Mexico, terminally ill patients or, if they are unconscious,

their closest relatives are permitted to refuse medication or further medical treatment to extend life in Mexico City, the central state of Aguascalientes, and the Western state of Michoacán.^{92,108–110}

In Italy, active euthanasia is under the penal law (as being equated to intentional homicide), as is assisted suicide. Nevertheless, the extensive use of pain-relieving drugs, which could cause premature death (i.e., indirect euthanasia), is not considered a form of euthanasia; neither is the abstention from aggressive treatments (i.e., those therapies that can only prolong a state without chances of amelioration). The Italian government is still in the developmental stage in regard to right to die policy, but theirs is mainly directed at limiting an individual's personal autonomy and the possibility of writing a personal living will. Indeed, advanced care directives, which are not yet broadly recognized in Italy, probably represent the best way to safeguard the principle of autonomy.

AUTHORS' POINT OF VIEW AND FUTURE PERSPECTIVES

We believe that all patients with DOC (i.e., their surrogates) should be put in the position to freely choose their own way to end their lives, in full respect of the personal and inviolable principles of the dignity and sanctity of human life. In our opinion, all patients should be free to manage their own deaths, or to empower someone to do it if they are incapacitated, when they perceive their quality of life as severely impaired by physical or psychological suffering (e.g., incontinence, nausea and vomiting, breathlessness, paralysis, difficulty in swallowing, depression, fearing a loss of control or dignity, feeling like a burden, having a dislike for being dependent) and when there is no chance of improvement.

It is urgent that governments establish safeguards, criteria, and protocol that protect the right to a

worthy death (in keeping the patient's lucid and conscious will and the personal concepts of dignity and the sanctity of life), ensure societal oversight, and prevent euthanasia and PAS from being abused or misused (i.e., moving from being a measure of 'last resort to one of early intervention').¹¹¹ In fact, euthanasia is progressively moving from terminally ill people to those who are chronically ill, and from physical illness to mental illness or psychological distress or suffering (even "tired of living"), and from conscious to unconscious patients. This means that the actual laws may fail to detect and prevent situations in which people could be subjected to undue pressure to access or provide euthanasia and could circumvent the safeguards that are in place.

A balanced law should guarantee and regulate the access to euthanasia/PAS. Such laws should require that all patients and their surrogates are properly educated regarding the law and their rights and are capable of making ELDs. Hence, ELDs must be voluntary, well considered, informed, and, above all, persistent over time. The requesting person must have provided explicit, written consent and must be competent at the time the request was made. In this regard, some states require that the voluntariness of the request has to be confirmed by at least two witnesses.

A law would avoid non-voluntary euthanasia in patients with DOC by confirming the lack of chances of recovery based on an accurate clinical assessment corroborated by advanced paraclinical approaches and by demonstrating the will of the patient to not live in such a condition. In cases with no living will in place, the best interest of the patient should be pursued according to evidence-based medicine and the opinion of the patient's surrogate.

The role of the physician is imperative when making informed ELDs. Indeed, the so-called "therapeutic alliance" between the

patient and doctor should be fundamental in ELD (as well as in life) and only when this alliance enforces the patient's autonomy. Physicians have a great responsibility to use their knowledge and skill in the primary interest of their patients, and should not only aim to relieve the burden of sorrow but also strive to educate and enable patients and their loved ones to understand, evaluate, and make their own choices concerning ELD. Only trained healthcare clinicians can make evidence-based diagnoses and prognoses of DOC conditions, thus the determination made by the physician on whether a DOC patient has any chance to improve is evidence-based and carefully considered. The pivotal role the medical staff plays in ELDs has been highlighted and regulated in countries where euthanasia and/or PAS are legal. Switzerland, however, allows non-physicians to assist in suicide. In the Netherlands and Belgium, a second doctor must see the patient to confirm the request to die is valid and the suffering unbearable, and a network of doctors is trained to undertake these consultations. In the United States, in all five of the states that allow PAS, it is required that a second doctor must examine the patient to confirm the terminal illness before the request is approved. In Oregon, Washington, and Vermont, the patient must also see a mental health professional when either the attending or consulting doctor suspects that the patient may be suffering from a psychological disorder (such as depression) that is impairing his or her judgement. In addition, ad hoc committees (even if this is delayed) are used to revise cases with potential mistakes in the euthanasia or PAS procedures. Unfortunately, these committees are largely underutilized.

Governments and magistrates must work to establish and communicate the proper protocol for ELDs to their citizens in order to guarantee the rights of patients to a

peaceful and worthy death and to limit SSA. Indeed, no additional requirement relating to the patient's experience of the disease or any minimum level of suffering would easily extend the application of euthanasia. On the other hand, narrowing euthanasia to unbearable suffering would limit the accessibility of the right to die for all the other patients. Likewise, limiting the right to die from a terminal illness (as in the United States) could result in the courts excluding patients with VS from this right, given that they are not terminally ill and their prognosis can only be established with sufficient confidence using advanced, non-standard neurophysiological or neuroimaging approaches. In addition, the acceptance of solely passive or indirect euthanasia for patients in VS would limit their accessibility to their right to die. In fact, these patients deserve the same accessibility to the right to die as other people and do not deserve a "worse" euthanasia than the others (i.e., a slow and agonizing death because of starvation and dehydration).

Finally, the people who have the duty of informing and educating the public seek to help people cope with the finiteness of the human condition, the intrinsic limits of medicine, and the responsibility to explore the values surrounding ELDs.

Hence, there is no reason why any single moral view of physicians, magistrates, politicians, or educators should prevail. A conciliation of the different currents of thought on euthanasia may be reached by placing, at the center, the patient's rights to freely manage his or her life and death while keeping the principles of dignity and sanctity of human life intact. ELDs should be guaranteed in patients with DOCs when negative prognoses have been well defined, possibly through the use of advanced neurophysiological and functional neuroimaging techniques, and the desires of the patients to not live in such

conditions have been clearly expressed by living wills or by surrogates. Finally, ad hoc committees to oversee the proper access and application of euthanasia should be instituted and potentiated.

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